TuSalud

Clinical Trials Are Testing Cancer Drug Rapamycin for Long COVID and ME

People who have tried the drug off-label in low doses report a range of experiences.

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Key points you should know:

- Two clinical trials are currently underway in the U.S. to evaluate the effect of rapamycin on long COVID and myalgic encephalomyelitis (ME) — one at Mount Sinai's Cohen Center for Recovery from Complex Chronic Illness and another at Simmaron Research.
- Rapamycin, also known as sirolimus, is a powerful immunosuppressant used to prevent organ-transplant rejection and to treat cancer.
- Mechanistic studies suggest that rapamycin can restore autophagy and mitochondrial function in people with ME.
- A few physicians prescribing low-dose rapamycin off-label for Long COVID and ME report positive effects for a subset of patients and no severe side effects.
- People taking rapamycin for Long COVID and ME report a range of experiences, including sustained responses, miraculous improvements followed by relapse, and side effects that lead them to discontinue the drug.

Last year, Reddit user Dry-One-8770 published the following post: "From bed bound with severe post-exertional malaise to playing basketball in six weeks: a rapamycin success story."

Dry-One-8770, a 26-year-old based in California who asked to be called Alex, developed long COVID after an infection in March 2022. He tried low-dose naltrexone and every supplement he could get his hands on. But he couldn't find a physician who would prescribe rapamycin, a drug that was emerging as a study target for the disease. "They laughed me out of the room," said Alex in an interview.

So, last summer, he went to a telehealth provider called Healthspan that specializes in supplying rapamycin for longevity. “It was at my door within two weeks,” he said. Initially, each weekly 5-milligram dose was followed by an intense headache, but this faded away over time. He had a few mouth sores too, a common side effect of the drug.

At first, Alex was cautious and did not purposely leave bed to exercise. But then, when he accidentally overdid it, he noticed that he wasn’t being punished with post-exertional malaise. Rapamycin “has been the only thing that has worked, and it is nothing short of a miracle,” Alex wrote on Reddit.

But six months after starting the drug, Alex began feeling sick after exercise. He has now stopped taking rapamycin and relapsed. “I’m essentially back where I was before,” he said. Despite this major setback, Alex is feeling confident that an effective treatment for long COVID is just around the corner.

Rapamycin is a potent anti-cancer drug and immunosuppressant that has been used to prevent organ rejection for decades, usually at a dose of a few milligrams per day.

Rapamycin was first discovered in the 1970s inside bacteria isolated from soil samples taken from Rapa Nui (also known as Easter Island), a remote volcanic island in the South Pacific Ocean. The drug was almost lost to history after a pharmaceutical company abandoned the research, but a rebel scientist rescued samples from the trash and eventually reignited interest in the drug. More recently, animal experiments have revealed rapamycin’s tantalizing potential as a longevity drug.

Now, scientists are investigating it as a treatment for long COVID and myalgic encephalomyelitis (ME). Two clinical trials are currently underway — one led by Simmaron Research in Nevada and another by Mount Sinai’s Cohen Center for Recovery from Complex Chronic Illness (CoRE) in New York.

But some physicians who treat long COVID and ME aren’t waiting for these study results to start prescribing the drug, which they consider low-risk at low doses and helpful for some people with these diseases.

Like any potential treatment, however, it is unlikely to work for everyone. One person with ME who spoke to The Sick Times anonymously reported significantly worse symptoms after trying it.

“I am hopeful that at least a subset of the people in the trials are going to improve,” Alex said.

ME trial has promising early results

Simmaron Research provided a sneak peek into its ongoing clinical trial via a preprint in June. Among 40 people with ME taking low-dose rapamycin over three months, 29 (72.5%) showed improvements in fatigue, post-exertional malaise, and orthostatic intolerance. The clinical trial will include around 120 participants overall and is expected to take as long as two years.

Ziyad Al-Aly, a physician-scientist and clinical epidemiologist at Washington University in St. Louis who is not affiliated with the trial, noted that "it cannot definitively determine whether rapamycin works or not in people with ME" as it is not using a placebo or randomization. Simmaron Research is actively seeking funding to run a larger randomized controlled trial.

Researchers are interested in rapamycin because mechanistic studies suggest it could target a biological pathway seen in people with ME. In this pathway, a protein called mTOR is overactivated, possibly leading to disruptions in a process known as autophagy in which cells reenergize themselves by replacing old and dysfunctional structures with brand-new parts.

Scientists at Simmaron Research suspect cells can't renew energy-producing mitochondria rapidly enough when the mTOR protein blocks autophagy — and thus ME patients' muscles fatigue faster than normal. Rapamycin reverses this process by blocking the mTOR protein.

The clinical-trial participants in the ME study who responded best to rapamycin were those who had a history of viral infection or reactivation, or noticeable shifts in blood biomarkers associated with autophagy.

If this finding holds up with further research, clinicians could use blood tests to screen patients for potential treatment with rapamycin, which "would be a huge advance," said clinical trial participant Catherine Romatowski, a member of the Patient-Led Research Collaborative.

Romatowski developed ME two decades ago, became bedbound in 2019, and "lost the ability even to whisper" following a crash in 2021. Two years later, she developed long COVID and deteriorated even further.

But within a few months of joining the rapamycin trial last year, "I was able to whisper briefly but reliably to my caregiver, which was extraordinary after years of silence," said Romatowski. A bad crash at the end of May reversed that improvement, but Romatowski thinks rapamycin might still be having an effect, as she's slowly improved since then.

To run the clinical trial, Simmaron is partnering with AgelessRx, a for-profit telehealth company that provides rapamycin as an off-label anti-aging treatment to more than 5,000 people in the United States. While the trial is still recruiting, it is by invitation only as of late July. Earlier participants paid for physician monitoring and regular bloodwork, but Simmaron is now covering these costs, a representative from the company told The Sick Times.

The company is also exploring other mTOR inhibitors, such as the diabetes drug metformin, for clinical trials.

CoRE's trial tests rapamycin for long COVID

A separate clinical trial at Mount Sinai's CoRE received an "overwhelming response" from the long COVID community when it started recruiting in April, said David Putrino, the director of the clinic.

The three-month randomized controlled trial will include 90 participants and track numerous factors, including changes to quality of life, cognitive function, post-exertional malaise, and autonomic and immune function.

Half of the participants will start on one milligram per week of rapamycin and titrate up until they reach a four-milligram weekly dose; the rest will take a placebo pill. “We also monitor blood levels for rapamycin itself to ensure it doesn’t hit an immunosuppressive dose,” said Putrino. The trial is expected to conclude in November 2026.

At high doses, rapamycin suppresses the immune system. But at low doses, it seems to have the opposite effect, correcting T-cell exhaustion, abnormal immune system regulation, and dysfunctional white blood cells known as natural killer cells — issues that have all been identified in people with Long COVID, said Putrino. Rapamycin could give the immune system the kick it needs to eradicate lingering infections and viral fragments in people with long COVID, he said.

The CoRE trial “seems to be very well designed,” Al-Aly said.

Highs and lows from off-label use

Stunning stories of improvement like Alex’s have encouraged some people with long COVID and ME to try rapamycin. A few physicians are also prescribing it off-label, but — as the drug is not approved for either disease — these doctors are the exception rather than the rule.

Kelly, a 40-year-old living in New York City who is sometimes bed-bound because of long COVID and ME, accessed rapamycin through AgelessRx in November 2024. “It’s been a slow process, but within a week, I was having some improvement in my symptoms,” she said. (Kelly, and other sources with long COVID and ME, asked to be referred to by their first names only.)

Caitlin, a 33-year-old with ME in Australia, was prescribed rapamycin in 2019. The difference in her physical limitations was “night and day”, she said. However, after three months, she experienced side effects, and by mid-2021, she had “lost hope of it working again.”

Wade, a 32-year-old with long COVID in Nashville, Tennessee, accessed rapamycin through Healthspan and took his first dose in March this year. After an initial negative reaction, “I felt great in a way I hadn’t for months,” he said. “I must have climbed the stairs in my house four or so times that day. I was almost completely bedbound at the time. So that was nothing short of a miracle.”

But allergies and mouth sores caused Wade to stop taking rapamycin after the third week.

Tania Dempsey, an internal medicine physician and complex disease specialist, has been treating people with ME since 2011 and started prescribing rapamycin over the past year. “When you have

patients who are not responding to anything else and are suffering, you have to start thinking outside the box," she said.

At first, Dempsey considered rapamycin only for patients who had tried all other drug options. "Whereas now I will consider it much earlier on," she said. A few of her patients have had an "impressive" response to the drug, she said, but "it's obviously not for everybody."

Some people with ME and long COVID can be highly sensitive to new medications, she said. "I'm not saying I wouldn't use [rapamycin], but I would be very, very cautious, just [because] I know historically how they react."

Danilo Buonsenso, a pediatric infectious disease physician at Gemelli University Hospital in Rome, Italy, started prescribing low-dose rapamycin off-label in December last year for people with very severe long COVID who had tried all other therapies.

"It is not ethical to leave such sick patients without treatment," said Buonsenso. Some of these patients "have the same quality-of-life impairment of oncologic patients, for which there is always an attempt for therapy also when doctors know that the disease is not curable," he said.

So far, those started on low-dose rapamycin for long COVID "have had great benefits," including returning to daily activities, Buonsenso said. He has not seen any severe side effects. Still, he said, "trials are needed and welcome."

David Kaufman, an internal medicine and chronic disease specialist, started prescribing low-dose rapamycin for people with ME about three years ago and quickly moved to prescribing it for long COVID. "I saw significant improvements in about two-thirds of patients," he said.

When the six-milligram-per-week dose of rapamycin worked, the effect was dramatic; some people who were previously bed- or housebound could resume daily activities, he said.

Kaufman knows that some physicians might call him a "cowboy" for prescribing rapamycin for long COVID. But the doses he recommends are one-eighth of those used for transplant patients, meaning the risks are much lower, he said.

People must take regular breaks from rapamycin because the protein complex inhibited by the drug — mTORC1 — has an important biological function, said Kaufman. Continuous use of rapamycin can also block another vital protein complex called mTORC2, leading to diabetes-like symptoms. However, blood tests show that a single low dose of rapamycin clears the body within a week, so people on this dosing regimen are already taking time off, said Kaufman.

The uncertainties around ME and long COVID remind Kaufman of his experience treating people with HIV in Manhattan in the 1980s. "It opened my mind [to the idea that] we don't know everything, but that doesn't mean we just give up," he said.

Kaufman was involved in more than 20 clinical trials for HIV and saw "miraculous treatments"

emerge, along with new insights into biology and immunology “that have applied across the board to everything about human medicine.”

“I think the same thing will happen with long COVID,” he said.

Felicity Nelson is a science and medical journalist with long COVID based in Sydney, Australia. She has written for Nature, C&EN, ScienceAlert, Veritasium, and The Guardian.

This story is part of a series about promising long COVID treatment trials and how they are designed. To share tips or feedback for the series, reach out to us at editors@thesicktimes.org.

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